The Impact of Palliative Care on Bereaved Family Members

Research Thesis

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Introduction:

Coping with the death of a loved one is a challenging experience for surviving family members. Although many people experience grief in a normal, non-pathologic way, others develop prolonged distress in the form of depression (1, 2), complicated grief (3), or posttraumatic stress disorder (PTSD) (4). The health consequences of these syndromes are far reaching, with the most concerning being a significantly increased rate of suicide in individuals with PTSD (5, 6) and depression (7, 8, 9). Complicated grief is identified by symptoms of intrusive thoughts, preoccupation with thoughts of the deceased, distressing yearnings, and disinterest in personal activities (10, 11). Complicated grief increases rates of medical illness and physician visits (12, 13). Psychological distress may impair family members' grieving process and quality of life.

Experiencing a loved one's death in a hospital can be especially distressing. Previous studies have indicated that family members of those who die in a hospital setting are at increased risk for poorer mental health, quality of life, and bereavement outcomes than those whose loved ones die at home or in hospice care (14, 15). Approximately 67% of individuals die in an acute care versus a home setting (16) such that the majority of the U.S. citizens will experience a death in the hospital with increased risk of psychological distress for family members. Unmet hospital-based needs of family members include lack of information (17), missing work to stay with their hospitalized loved one (18), and financial difficult related to medical expenses (19).

Palliative care is a medical specialty offering interdisciplinary services to alleviate the suffering of patients with serious illnesses and their family members. Palliative care

is “focused on preventing, treating and relieving the debilitating effects of serious and chronic illness” (20). Once confined to providing comfort to the dying, palliative care has broadened to include services to address the physical, social, psychological, and spiritual concerns of family members. Palliative care may begin with initial treatment by providing optimal symptom management and can continue throughout the disease trajectory. The positive impact of palliative care is well documented, including improving patient pain symptoms and patient satisfaction with care (21, 22, 23) as well as decreasing hospital costs (24, 25). Furthermore, a recent study showed that palliative care provided from the time of diagnosis for lung cancer patients may increase patient survival in addition to benefitting mood and quality of life (25).

Palliative care services have the potential to benefit family members as well. For instance, the focus on enhanced communication may reduce poor communication between health care providers and family members, which has been shown to be a risk factor for depression and PTSD in cancer patients’ family members post-death. One study in the ICU showed a 24% reduction of PTSD symptoms in family members when communication was enhanced compared to controls by using a communication intervention (22). Although research has demonstrated the positive impact of palliative care on a variety of patient outcomes (25, 26, 27), fewer studies focus on whether palliative care is beneficial for family members. Research has not yet explored which specific hospital experiences contribute to family member psychological distress. To address this gap in the literature, the goals of this project were to (1) to investigate whether palliative care helps decrease depression, PTSD, and complicated grief in family members of chronically ill patients, and (2) to investigate if the issues most distressing to

family members during their last hospital stay were addressed by health care providers. We hypothesized that having a palliative care consult in the final days of a family member's life would result in fewer reported symptoms of depression, complicated grief and PTSD for family members in post-bereavement period.

Methods

Study Design

This study utilized a non-randomized, matched-control design that investigated whether receiving a palliative care consult in the last week during a loved one's life in the hospital resulted in fewer reported symptoms of depression, complicated grief, and PTSD for family members post-bereavement. The analyses compared a group of families who received palliative care (PC) and a group who did not (Non-PC). This study also examined how often distressing end-of-life events were directly addressed by a health care professional. Approval was obtained from the Institutional Review Board at the Wexner Medical Center at The Ohio State University. All participants provided written informed consent.

Participants

Participants were family members of patients who died at a large 1,182-bed Midwestern hospital between April 1, 2009, and December 31, 2012. Patients ranged in age from 21 to 92 with an average age of 66 years (*SD*=14.1). The average length of the patients' last admission was 14 days (*SD*=17.7). Seventy-eight (62%) patients died in the intensive care unit. Ages of participants ranged from 23-84 years. Most participants were

middle-aged Caucasian females who were spouses of the deceased. See Table 1 for further demographic and disease information.

Procedure

Recruitment

Participants were recruited if they were between three and eighteen months after their loved one died and if they were listed as the next-of-kin in the deceased patient's medical record. Eighteen months from the point of the patient's death was chosen as the cut-off because most hospice programs offer bereavement services for thirteen months, and we sought to determine the bereavement needs six months after the first anniversary of the loss to determine needs that may continue to exist beyond this date. Requests for participation were included with a three-month bereavement support group informational letter that is sent to all families experiencing a death in the hospital. Participants were eligible for the study if they were older than 18 years of age, were able to communicate in English, and consented to complete the survey.

Participants were invited to complete study questionnaires via mail, telephone, or in-person interview. If we did not receive a response from our mailed invitation, family members were sent an additional letter one month later reminding them of the study. If family members did not respond after the follow-up letter, no further contact was attempted. Participants were mailed study questionnaires or scheduled for a phone or in-person interview, according to their preference. All participants completed the same five questionnaires. Family members filled out the questionnaire after an average of nine months (*SD*=5.0) following their loved one's death.

Two hundred thirty six individuals agreed to participate. Of these, 136 participants (58%) completed questionnaires. Data from eleven of these participants were not included in the current analyses because their loved one spent less than 24 hours in the hospital before their death, which did not allow for sufficient time in the hospital to report each hospital end of life experience. Therefore, the final number of completed questionnaires was 125. One hundred and seven (86%) participants completed their questionnaire by mail, 10 (8%) over the phone, and 8 (6%) in person. Because so few participants completed the questionnaire over the phone or in person, data was not available to compare results within method of questionnaire and all were combined in the analyses.

Matching

Participants who received a palliative care consult in the last week of their loved one's life (PC group) were matched with participants in our sample of respondents who did not receive palliative care (Non-PC group) in order to control for the following respondent characteristics previously associated in the literature with our outcomes of depression, complicated grief, and PTSD: race, relationship to the deceased, gender, patient diagnosis, history of psychological diagnosis, and age (within 20 years) (2, 4, 28, 29, 30). The two groups were successfully matched in almost all cases: race (96%), relationship to the deceased (90%), gender (95%), patient diagnosis (91%), presence of psychological diagnosis (87%), and age (95%). Thirty-three participants received a palliative care consult; each participant in the PC group was matched with three

participants from the study in the Non-PC group, for a total subsample of Non-PC of n = 92.

Measures

Sociodemographic information. Socio-demographic information was obtained from family members via standardized survey including gender, age, ethnicity, religion, education, relationship to the deceased, closeness to the deceased, history of mental health diagnoses, employment status, financial difficulties related to medical expenses, and when the deceased was diagnosed.

Patient hospitalization information. Relevant medical data of patients, such as disease status, place of death, and cause of death were obtained from hospital deceased lists used for support group mailings. This information was verified via a review of physician consult notes for each patient.

Family member depressive symptoms. We assessed family member depressive symptoms using the Center for Epidemiologic Studies Depression Scale (31). This is a widely-used 20-item questionnaire which asks respondents to rate the frequency of their depressive symptoms (e.g., "I felt depressed.") on a scale from *0 = rarely or none of the time (less than 1 day)* to *3 = most or all of the time (5 to 7 days).* Scores range from 0 to 60 with higher scores indicating greater levels of depressive symptoms. A cutoff of 16 has been used in previous studies to indicate probable depression, with moderate depression

indicated by a score higher than 19 and severe depression indicated by a score above 31 (31). Cronbach's alpha for the current sample was $\alpha = .89$.

Family member complicated grief. Complicated grief was assessed using the Inventory of Complicated Grief – Revised (Prigerson, 1995) a 19-item self-report questionnaire that assesses symptoms on a five point scale from 0-4. The rate of Complicated Grief was computed by summing ICG-R items, with scores greater than 25 points used as a cut-off for complicated grief (32). This questionnaire has high internal consistency and test-retest reliability (0.80 for both) in previous studies (32). For this study, Cronbach's alpha was .93.

Family member posttraumatic stress disorder symptoms. Post-traumatic stress disorder symptoms were assessed using the Impact of Event Scale – Revised (IES-R). This is a 22-item self-report questionnaire that assesses the frequency of PTSD-related symptoms (intrusions, avoidance behaviors, hyperarousal) in the past week on a five-point scale from *1(not at all) to 5 (extremely)*. Higher scores indicate greater post-traumatic symptoms (33). The rate of PTSD was computed by summing IES-R items, with scores greater than 32 points used as a cut-off for PTSD (34). Test-retest reliability ranges from 0.57 to 0.87 (35, 36). For this study, Cronbach's alpha was .94.

Family Experiences at End of Life (FEEL). The "FEEL" questionnaire has been used to assess the incidence of common end-of-life experiences and the level of distress associated with these experiences. The 32-item questionnaire was developed based on difficult experiences observed by family members receiving palliative care, reported in the literature, and based on information provided by family members attending bereavement support

groups facilitated by one of the study authors (SWD). Our questionnaire was modeled on the Stressful Caregiving Adult Reactions to Experiences of Dying (SCARED) Scale developed by Prigerson and colleagues (2003), which has been shown to have excellent psychometric properties and is predictive of important clinical outcomes, such as major depressive disorder (3). FEEL lists 32 events or experiences that may have been and may continue to be distressing to the surviving family member. The FEEL includes questions about patient physical symptoms, end-of-life decision-making, patient emotional responses and staff interactions at the end of life, among others. The measure asks the participant to indicate whether each experience occurred during the final week of the patient's life. For endorsed events, participants rate associated distress (1=*none*, 2=*mild,* 3=*moderate*, 4=*severe*) at the time of the event. Previous research with 77 family members who experienced a death in the hospital (Weiskittle, under review) suggests that witnessing loved ones in severe pain, being unable to say goodbye, and family member disagreement over care were most distressing for family members at the time of the patient's death. For this study, we used items rated as most distressing from this previous study to construct a standardized chart review document allowing us to record whether these issues were addressed by medical providers during the final hospital stay. We reviewed all recorded notes written during the last week of life. Table 2 illustrates the top twenty most distressing experiences for family members from our previous study.

Medical Record Review. We reviewed the medical records of patients for the final week of their life to confirm whether a palliative care consult had occurred, and related to our second aim, to document which areas of distress were addressed in the final progress notes. A

standardized chart review form was created for this study collecting the following information: whether the patient was noted to have delirium, emotional distress, restlessness, lack of responsiveness, moaning, severe pain, shortness of breath, or rattled breathing, and if the family member made the decision to stop life-sustaining treatment, had family disagreement over care, or witnessed CPR. These areas of distress were selected based on our previous study suggesting these were within the top twenty distressing hospital events experienced by family members related to the care of the patient. Some FEEL items within this list were not included in the consult review because physicians do not typically include detailed notes on family member subjective emotional reactions and perceptions. These items include family member feelings of guilt over treatment, feeling loved one "had enough," being unable to say goodbye, and feeling staff were unavailable to address concerns.

Analyses

Descriptive analyses were completed to report palliative care consult characteristics, such as the total number of visits, length of consult time, and topics discussed. We computed chi-square tests for independence to evaluate whether significant differences existed between PC and Non-PC groups on demographic and disease variables. Preliminary assumption testing was conducted to check for normality, linearity, univariate and multivariate outliers, homogeneity of variance-covariance matrices, and multi-collinearity, with no serious violations noted for our primary outcome variables. We assessed group differences (PC vs. Non-PC) on depression, complicated grief, and PTSD with a multivariate analysis of variance (MANOVA) because our measures were highly correlated and to reduce Type I error rate. Univariate tests were completed based on significant results. Chi-square tests for independence were used

to determine whether health care providers addressed the distressing end-of-life experiences endorsed by family members.

Results

Palliative Care Consults. Thirty-three (26%) participants received a palliative care consult in the last week of their loved one's life. A palliative care team member met with families an average of 4 days before death (*SD*=4.6). The average time spent with a family was 84 minutes (*SD*=33.4). Families were most often met by a palliative care physician (94%) rather than a palliative care nurse (6%). The most commonly discussed topics were goals of care (88%) and the dying process (82%), with the most common stress of families being the dying patients' care (52%). During the majority of consults, the patient was unresponsive and the palliative care provider met primarily with the patient's family (85% of consults).

Sample Characteristics

PC vs. Non-PC Groups

There were no significant differences between demographic and disease characteristics of PC and Non-PC participants (see Table 1).

Psychological Distress. A one-way between-groups multivariate analysis of variance was performed to investigate reported differences between PC vs Non-PC groups. Three dependent variables were used: symptoms of depression, complicated grief, and PTSD. The overall MANOVA assessing depression, complicated grief, and PTSD between groups was statistically significant $F(3,120)=78.0$ $p<.05$, Wilk's $\Lambda = .94$, partial $\eta^2=.06$ (see Table 3).There was a statistically significant difference between PC vs Non-PC groups on reported symptoms of depression: $F(4, 119)=2.47$, $p<.05$, Wilks' Λ

=.92; partial η^2 =.03. An inspection of the mean scores indicated that family members who experienced a palliative care consult reported significantly fewer symptoms of depression (*M*=14.1, *SD*=11.1) than those who did not experience a consult (*M*=19.2, *SD*=13.0). There was not a significant difference on complicated grief between those who received a palliative care consult (*M*=21.1, *SD*=14.1) and those who did not receive a consult (*M*=23.0, *SD*=14.4). Family members who received palliative care also did not report significantly fewer symptoms of PTSD (*M*=22.1, *SD*=14.1) than those who did not receive a consult (*M*=27.2, *SD*=18.1).

Twelve (36%) PC participants scored above the cut-off for depression; 9% reported symptoms consistent with mild depression, 18% reported moderate depression, and 9% endorsed severe depressive symptoms. Fifty-two (57%) Non-PC participants scored above the cut-off for depression; 11% reported mild depression, 22% reported moderate depression, and 22% endorsed severe depression. Eleven (33%) PC participants and 37 (40%) of Non-PC participants endorsed symptoms of complicated grief. Seven (21%) PC participants and 32 (35%) of Non-PC participants reported symptoms meeting the clinical cut-off score for PTSD.

End-of-Life Experiences. Chi-square tests for independence revealed that PC participants were significantly more likely to have their loved one's symptoms of delirium addressed by physicians than Non-PC participants, (1,N=125)=0.XX, p <. 05. No other end-of-life experiences were addressed significantly more or less between groups. According to subsequent chi-square tests deciding to end life-prolonging treatment, patient delirium, patient moaning, and patient shortness of breath were

endorsed significantly more or less often than they were addressed. See Figure 1 for reported frequencies.

Discussion

Results of this study demonstrate that family members who received a palliative care consult within the last week of their loved one's life report fewer symptoms of depression than family members who did not receive a palliative care consult. Only 36% of participants who received a consult scored above the cut-off for clinically meaningful depressive symptoms, compared to 56% of participants who did not receive a palliative care consult approximately 9 months post-loss. There are several possibilities for this difference in depression levels. One potential explanation is that palliative care improves communication between health care providers and patient families about patient diagnoses and goals of care (22), and in doing so may alleviate fears of the unknown or feeling overwhelmed. Poor communication with health care providers is a common complaint among patient family members (37) and addressing this concern may positively affect many families' perception of the quality of patient care. Improving communication during the end of life could therefore alleviate some symptoms of depression in bereaved family members.

Another explanation is that palliative care may be one of the few hospital services offered that directly addresses the needs of the family as well as the needs of the patient. This approach may result in greater family member opportunities to voice their emotional concerns or to address questions about the future. Lastly, research supports that palliative care improve patients' quality of life by decreasing physical symptoms (21), and reported pain scores (24), as well as improving patient satisfaction with care (23). Family

members may grieve with fewer symptoms of depression when their loved one displayed less physical or emotional distress at the end of life. Perceiving that a loved one had a "good death," is very important to family members especially perceiving that the patient was comfortable, had good emotional support, and had less pain (37, 38). Palliative care offers the possibility of improved healthcare communication, meets patient and family needs, and alleviates patient stress, all of which may contribute to the significantly lower depression scores of PC family members.

In contrast, complicated grief and PTSD scores were not significantly different between those who received a PC consult and those who did not. Complicated grief has been predicted by attributes present far before the actual loss of a loved one, such as social role functioning and interpersonal relationship skills (39). Therefore, it is understandable that a palliative care consult at the end of life may not be able to alter the long-standing risk factors for developing complicated grief. In terms of PTSD, a patient's physician does not often request a palliative care consult until a few days before the patient's death. In this study, palliative care consultation occurred an average of four days before the patient's death. Previous studies have suggested that the pattern of late referrals restricts the effect of palliative care on patients and their families, and argue that services should be provided earlier in the course of the disease (24). Indeed, an earlier consult may reduce families' PTSD symptoms, particularly if stressful hospital experiences occur prior to four days before death.

Results of this study demonstrate that many bereaved family members endorse symptoms of distress. Thirty-six percent of PC participants and 57% of Non-PC participants scored above the cut-off for clinically meaningful depressive symptoms

(CES-D) which is consistent with rates reported in existing research of bereaved individuals whose loved one died in an institutional setting (1,2, 3, 15), but is significantly higher than rates reported in the general bereaved population, which suggests only 15-16% are depressed (40, 41, 42). Thirty-three percent of PC and 40% of Non-PC participants endorsed symptoms of complicated grief, which is typical per existing research (4, 10, 11). Twenty-one percent of PC and 35% of Non-PC participants reached the cut-off for PTSD, which is also consistent with rates reported in existing research of families who have lost a loved one in the hospital (4, 5).

In our prior study (Weiskittle, under review), the top twenty most distressing end-of-life experiences for family members included patient physical symptoms, deciding to end life-prolonging treatment, and witnessing CPR on their loved one, among others. For this study, we recorded how often these top distressing experiences were documented by a physician within the patient's consult notes to assess whether physicians were addressing these experiences and potential unmet family needs. When a need was noted within a doctor consult, it was addressed no less than 85% of the time, regardless of whether the family was PC or Non-PC. The high rate of physician attention to the most distressing family member hospital experiences may also contribute to the lack of difference between PC and Non-PC in complicated grief scores and PTSD scores: distressing events related to these syndromes were equally addressed by the primary and consultation teams for each group.

However, there are some discrepancies between how often distressing hospital experiences were reported by family members and how often they were noted by health care professionals in their consult notes. For some experiences, such as witnessing CPR

and witnessing the patient as restless or agitated, family members reported the events but the doctors often did not note these experiences in the last week of life. For other experiences, such as patient's shortness of breath and patient's delirium, physicians reported the symptoms more often than families reported the experience. There are several possibilities for these differences. For example, physicians may have been aware of certain events and did address them appropriately, but failed to write the experience within their notes. Physicians are likely more accustomed to witnessing these events and consider them expectable events during the dying process and therefore do not chart these experiences. It is also possible that certain distressing events occurred but the physician was not present or was not aware. For events endorsed more often by physicians than family members, the events perhaps occurred but were not memorable enough for families to recall them, or the family member was not present at the time of occurrence. These discrepancies may highlight the lack of communication that has been reported by family members. It is also important to note that while some end-of-life experiences were not found to be statistically significant, their reported differences may be considered clinically significant. Specifically, patient pain/grimacing was reported by 38% of family members and was addressed per physician notes in 23% of cases. Given that this is rated as one of the most distressing experiences, this discrepancy could create a long-term impact on family recall of the dying experience.

Several limitations should be addressed with future research. First, as with many bereavement studies, our response rate was 58%. This introduces the potential for response bias. It is possible that family members who are less psychologically or emotionally distressed by their hospital experiences may have been more likely to

respond, as those still experiencing immense pain about their loss may be less apt to discuss their feelings. This bias may indicate that we are under-representing the levels of psychological distress within our target population, which is concerning because our reported distress levels, although consistent with the literature, are already significantly higher than the normal bereaved population. Second, because our record of hospital end-of-life events were taken straight from physician consult notes, there is a risk that hospital experiences were not recorded accurately in the medical record. This may result in an underestimation of distressing experiences. Finally we described the average top ten most distressing experiences for family members, rather than rate how often individual participants' needs were met. Although this measurement provides an accurate summary of the overall most distressing hospital experiences, it lacks the detail necessary to analyze whether health care providers addressed each family members' unique set of distressing experiences.

Palliative care impacts patient quality of life, with studies reporting increased length of life, decreased pain, and higher quality of life in palliative care patients (21, 23). This study addresses an important gap in the literature on the effect palliative care on family members post-bereavement. It is crucial for hospitals to assess and provide care for patient family members, not only to improve their quality of life, but also because the family members will be future patients. Specifically, research should focus on better understanding family member complicated grief and PTSD and how to intervene to reduce these symptoms. Physician records provide some insight into describing the frequency of distressing events during the last week of life, but more research is required to investigate how these experiences directly impact family members long-term. Utilized

earlier in the patient and family end of life experience, palliative care could provide additional benefit to family members post-loss.

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Table 1
Demographic and Disease Characteristics of Family Members and Patients

Demographics	*N=33* *PC** *n* (%)/*M*(*SD*)	*N=92* *Non-PC* *n* (%)/*M* (*SD*)	*p-values*
Family Members (n=125)			
Age in years	58 (14)	59 (10)	.76
Female	25 (76)	75 (81)	.46
Ethnicity			.95
Caucasian	30 (91)	86 (93)	
African American	1 (3)	5 (5)	
Other	2 (6)	2 (2)	
Years of education	15 (3)	15 (3)	
Relationship to patient			.11
Spouse/Partner	16 (49)	62 (67)	
Daughter	8 (24)	17 (18)	
Mother	3 (9)	3 (3)	
Sister	2 (9)	4 (4)	
Son	3 (9)	6 (7)	
Niece	1 (3)	1 (1)	
Patients (n=125)			
Age in years	67 (17)	65 (14)	.30
Cause of death			.78
Cancer	18 (55)	47 (51)	
Heart disease	4 (12)	13 (14)	
Other	11 (33)	33 (36)	
Site of death			.68
ICU	11 (33)	41 (44)	
Non-ICU	49 (64)	21 (64)	
Length of Hospital Stay	20 (25)	12 (14)	.08

**Note*. PC=Received palliative care consult,
Non-PC= did not receive palliative care consult

Table 2
Top Twenty Average Distress Ratings for Family End of Life Experiences (FEEL) [a]
[a]*Note*. Total N=77

Experience	*M (SD)* Distress[b]	*n,* (%) experienced
Loved one in severe pain/grimacing	2.76 (0.44)	17 (22)
You were unable to say goodbye	2.74 (0.51)	31 (40)
Family members' disagreement about care plans	2.71 (0.76)	8 (10)
Witnessing efforts to re-start loved one's heart	2.69 (0.63)	13 (17)
Loved one fearful of dying	2.40 (0.70)	12 (16)
You were given mixed messages by different health care providers	2.37 (0.76)	19 (25)
Loved one anxious or fearful	2.36 (0.79)	23 (30)
Loved one fearful of being alone	2.36 (0.63)	16 (21)
Loved one sad or crying	2.33 (0.91)	21 (27)
Lack of responsiveness by loved one	2.31 (0.92)	62 (81)
Making the decision to stop life-prolonging treatment	2.25 (1.05)	58 (75)
Loved one gasping, severe shortness of breath	2.25 (0.68)	16 (21)
You felt loved one "had enough"	2.23 (0.86)	60 (78)
Loved one weak/unable to move	2.23 (0.69)	22 (29)
Loved one moaning	2.17 (0.80)	29 (38)
Increased mucous production/rattling with breathing	2.14 (0.73)	22 (29)
You felt that different therapy should have been provided	2.10 (0.72)	21 (27)
Lack of information about what to expect when loved one was dying	2.06 (0.83)	17 (22)
Your feelings of guilt over treatment choices	2.03 (0.90)	27 (35)
Staff unavailable to address concerns	2.00 (1.41)	5 (7)

[b]1=*None*, 2=*Mild*, 3=*Moderate*, 4=*Severe*

Table 3

MANOVA Summary Table--Effect of PC. Vs. Non-PC on Measures of Distress

Distress Measure	PC N=33	Non-PC N=92	DF	*F*	*p*-value
Depression	14.05	19.36	1	4.43	0.04
Complicated Grief	20.97	22.67	1	0.35	0.56
PTSD	22.09	27.54	1	2.43	0.12